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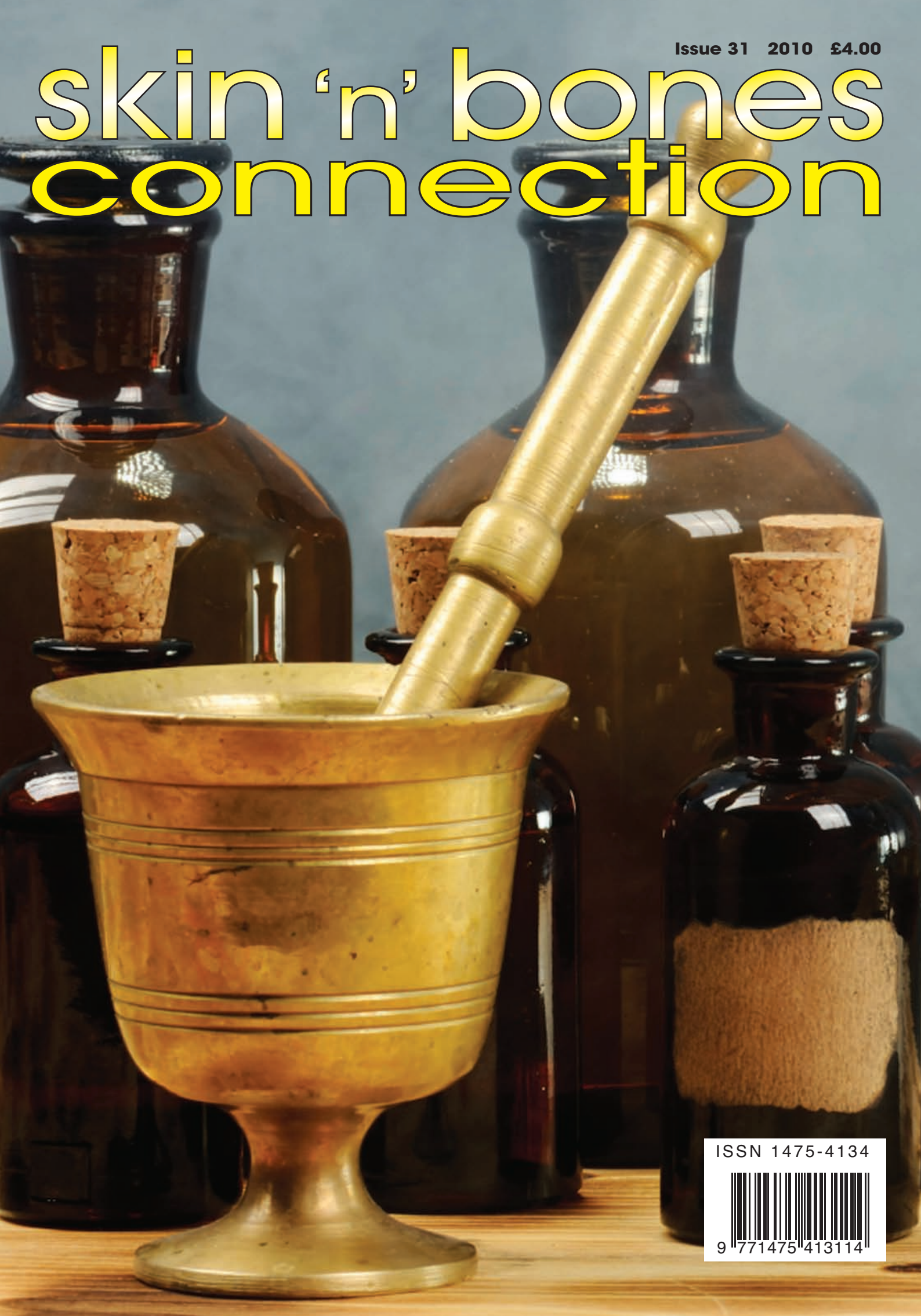
skin 'n' bones connection



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Dear Reader

In this issue we are pleased to focus on a couple of initiatives that are helping people with psoriasis and psoriatic arthritis.

There is also a report on the successful patient events held by the Queen Alexander Hospital Department of Rheumatology, Portsmouth, which have titles such as *living well with back and neck pain, living well on biologic therapies* and *love your bones* (see page 3).

On page 7 there is an article on the development of the integrated psoriasis and psoriatic arthritis service at the Royal Free Hospital in Hampstead, London. This is being spearheaded by Dr Arvind Kaur and Dr Sandy McBride. Some readers may know or have used the service previously, which owes great credit to consultant rheumatologist Dr Anthony White, who for many years pioneered the hospital's dedicated psoriatic arthritis clinic. Dr White has retired from the NHS but still carries out a successful private practice in London.

Our main feature on pages 10-12 is on genital psoriasis. This subject is one of the most searched items on our website and we've tried to cover this topic in a way that answers the common questions.

As always we are grateful to our contributors, and will continue to welcome articles and letters for inclusion.

Managing editor

The Psoriasis and Psoriatic Arthritis Alliance (PAPAA) is the new single identity of the Psoriatic Arthropathy Alliance and Psoriasis Support Trust The organisation is independently funded and aims to be a definitive source of information and educational material for people with psoriasis and psoriatic arthritis in the UK. To be a support to both patients and professionals by providing material that can be trusted (evidence based), which has been approved and contains no bias or agendas. We will be looking to provide positive advice that enables people to be involved as they move through their healthcare journey in an informed way, which is appropriate for their needs and any changing circumstances.

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Cover Photo:
Alchemy – old fashioned healthcare and medicine.

Patients' event

For the past three years the Department of Rheumatology at the Queen Alexandra Hospital, Cosham, has held 15 patient and public conferences. These have been recognised as pioneering events within the field of rheumatology. In 2009 the National Audit Office also acknowledged the conference / programme as an innovation in its report on rheumatoid arthritis to Parliament.

The team is dedicated to ensuring that patients receive the latest information on medication, treatments, nutrition and exercise to improve the quality of their daily life. Patient conferences are tailored to fit individual needs and feature question and answer sessions with physicians and other healthcare professionals, patient support groups, and invited uplifting motivational speakers.

The conferences are also a time to get together as a community. They give individuals and families the chance to meet one another and share common experiences. The team works with all ages, from children through to working adults and older people.

These events enable the rheumatology team working with Portsmouth Arthritis and Musculoskeletal Alliance (ARMA), a local network group, to firmly commit to building our relationship with all patients and their families, healthcare professionals, council departments and patient support groups.

The Day to Day Living with Arthritis event last December attracted more than 450 delegates and during the past three years more than two thousand delegates have attended a variety of one-day and evening conference/events.

Feedback from attending delegates has been so positive and encourages the team to look towards future events. 90-98% of patients attending state they would go to similar events.

Conference delegates say the friends they made and the information they received changed the way they think about their disease and how they manage it. For first-timers, the ability to meet other people with similar diseases is an inspiring experience. They gain confidence knowing that others manage the disease and that there is hope for them.

Recently other departments from the trust have supported these events, including spinal orthopaedic services, infection control team, bowel cancer screening team and equality and diversity – these too have been well received by the delegates.

NEXT EVENTS:

30th June 2010 -
Love your bones - osteoporosis update

6th October 2010 -
Day to day living with arthritis - for people with all types of Arthritis.

Break out sessions - Pain and arthritis
Skin and arthritis

For further information please contact:
Colin Beevor, Matron on 023 9228 6000 ext 1495
Musculoskeletal OPD Services,
Rheumatology Department, Queen Alexandra Hospital,
Cosham PO6 3LY
www.porthosp.nhs.uk

Note: **PAPAA** will have a patient information stand at these events – why not come along and say hello?

Do you remember the first time, as a child, you had to visit a doctor or go to hospital? Even as adults this can be a confusing and stressful situation. As a child, sometimes it's a big adventure but more likely a confusing and distressing process.

Oxford University Press have a series of books aimed at pre-school and infant readers called First Experiences, as part of the popular Read at Home Oxford Reading Tree. It's the most successful reading scheme in the UK, used to teach reading in 80% of schools.

The titles in the First Experiences series cover situations which include visits to the hospital, the doctor and the dentist. Other titles are related to events such as starting school or going to the swimming pool.

Read at Home is the best-selling home reading series designed for young, beginner readers. It features all the popular Oxford Reading Tree characters in exciting stories written for parents to support their children's reading at home. Read at Home First Experiences introduce young children to new situations and are ideal for both parent and child to read together.

For example, in At the Doctor (Level 4), Kipper is unwell and goes to the doctor for the first time

Read at Home First Experiences help parents to:

- **Explore the wider world with their child**
- **Talk about shared feelings and emotions**
- **Build vocabulary through the fun activities**
- **Help to take the distress and mystery out of first time visits**

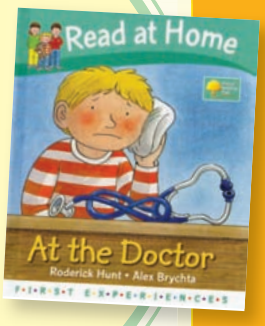
Each story provides a range of fun activities to encourage discussion and support reading skills:

A puzzle activity in every book to make reading fun and practise looking at detail.

A game or fun activity like a maze or spot the difference provides a treat for children to enjoy at the end of the story.

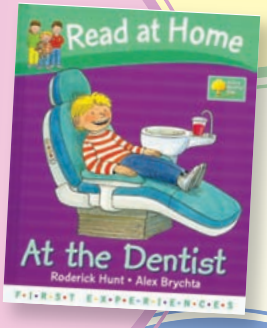
Read at Home: First Experiences: At the Doctor

978-0-19-838663-6
Hardback | 06 September 2007
Price: £2.99



Read at Home: First Experiences: At the Dentist

978-0-19-838641-4
Hardback | 03 May 2007
Price: £3.50



Read at Home: First Experiences: At the Hospital

978-0-19-838723-7
Hardback
01 January 2009
£3.50

Series of books from Roderick Hunt, co-author and series editor Annemarie Young, illustrator Alex Brychta, and series editor Kate Ruttle.

A full list of titles is available from Oxford University Press.

These titles are also available in bookshops and online retailers such as
Amazon - www.amazon.co.uk
The Book People - www.thebookpeople.co.uk
Oxford University Press - http://ukcatalogue.oup.com/

Psoriasis treatments

As the first in a series of occasional articles, we thought we would look at topical (applied to the skin) psoriasis treatments, some of which may have been forgotten or overlooked.

Although psoriasis is a chronic long term condition with no cure, it can be controlled and go into remission (go away). Not all people will be affected in the same way and doctors will class the condition as mild, moderate or severe. The following are the different types of treatments you may be offered. Please note these are listed alphabetically and not in the order of use, and are for reference only. Always follow your healthcare provider's advice.

Antifungals

The use of antifungal agents in psoriatic care tends to revolve around the treatment of seborrhoeic dermatitis and scalp psoriasis.

They are used to remove the fungus pityrosporum ovale, more recently known as malassezia, which has been linked to conditions such as dandruff and scaly scalp conditions. Some commonly used anti-dandruff shampoos claim to have active ingredients which fight these microbes.

Prescribed anti-fungal can be used alone or in combination with topical corticosteroids, an antibacterial or both. They are sometimes incorporated into a treatment regime to prevent fungal infection on skin which could be prone to it.

Coal tar

Coal tar therapy has been used for well over a century in dermatology.

It is a topical treatment mostly used for acute scalp psoriasis. It has anti-inflammatory properties that are useful in chronic plaque psoriasis; it also has anti-scaling properties. Crude coal tar (coal tar, BP) is the most effective form, typically in a concentration of 1 to 10% in a soft paraffin base, but few outpatients tolerate the smell and mess.

Cleaner extracts of coal tar included in proprietary preparations are more practicable for home use but they are less effective and improvement takes longer.

Contact of coal tar products with normal skin is not normally harmful and they can be used for widespread small lesions; however, irritation, contact allergy, and sterile folliculitis can occur. The milder tar extracts can be used on the face and flexures. Tar baths and tar shampoos are also helpful.

Coal tar has also been used in combination with ultraviolet B light in hospitals and is known as the Goeckerman method.

Combination therapies

Sometimes clinicians will prescribe a product containing one or more active ingredients with different functions. This may be in order to simplify the number of treatments being applied at any one time or because the agents combined together have been shown to act better than when used independently.

Dithranol

Dithranol has been used for more than 100 years in the treatment of psoriasis. It is a chemical of plant origin, taken from the bark of a South American tree.

Dithranol in Lassar's paste is used most successfully for inpatients in the hospital environment. However the use of dithranol is not without drawbacks. Dithranol permanently stains both skin and clothing and can burn non-affected skin.

Whilst this can be controlled by careful application in hospital its compliance is poor when used as outpatient therapy. There are also a large number of concentrations for doctors to use and the tendency has been for patients to be prescribed different concentrations in either a 'step up' or 'step down' fashion.

Proprietary dithranol containing products are more acceptable. They can be used in 'short contact regimes', being applied to the psoriatic plaques and left for up to one hour before washing off. This method reduces dithranol burning and staining.

Emollients

Emollients soothe, smooth and hydrate the skin and are indicated for all dry or scaling disorders. Their effects are short-lived and they should be applied frequently even after improvement occurs. They are useful in dry and eczematous disorders, and to a lesser extent in psoriasis.

Light emollients such as aqueous cream are suitable for many patients with dry skin but a wide range of more greasy preparations including white soft paraffin, emulsifying ointment, and liquid and white soft paraffin ointment are available; the severity of the condition, patient preference and site of application will often guide the choice of emollient. Emollients should be applied in the direction of hair growth.

Some ingredients may rarely cause sensitisation and this should be suspected if an eczematous reaction occurs.

Preparations such as aqueous cream and emulsifying ointment can be used as soap substitutes for hand washing and in the bath; the preparation is rubbed on the skin before rinsing off completely. The addition of a bath oil product may also be helpful.

Preparations containing an antibacterial should be avoided unless infection is present or is a frequent complication.

Urea is employed as a hydrating agent. It is used in scaling conditions and may be useful in elderly patients. It is occasionally used with other topical agents such as corticosteroids to enhance penetration.

Retinoids

Retinoids are a derivative of vitamin A and can be used both orally and by direct application to the skin. They should not be confused with the vitamin A products that are bought from chemists or supermarkets as vitamin supplements.

The topical retinoid tazarotene is used for the treatment of mild to moderate plaque psoriasis. It binds to nuclear retinoic acid receptors in the skin, promoting normal differentiation of skin cells and reducing the formation of patches of raised skin.

It also reduces the formation of cytokines and interleukins, two chemicals in the body that are responsible for causing inflammation. In other words it acts by reducing the inflammation AND reducing the rate at which skin cells develop plaques.

Tazarotene's specificity and its low systemic absorption means that it produces fewer side effects than the earlier retinoids. It has a half-life of only 18 hours and does not accumulate on repeated administration.

Steroids and corticosteroids

Topical steroids are used for the treatment of inflammatory conditions of the skin (other than those arising from an infection).

They are effective in conditions such as eczema and psoriasis. They are of no value in urticaria or pruritus (itch) and will make the symptoms of rosacea and acne worse.

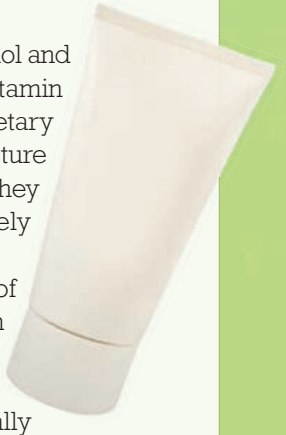
Corticosteroids act by preventing phospholipid release from the cell membrane and thus prevent their conversion via arachidonic acid into prostaglandins and other chemicals which cause inflammation.

Corticosteroids only suppress the inflammatory reaction during use; they will not cure the condition and the skin problem may get worse once the use of topical corticosteroids stops. This is called a rebound effect. They are generally used to relieve symptoms and suppress signs of the disorder when other measures such as emollients are ineffective.

Over the years a number of topical corticosteroids have been developed of different strengths. They are now categorised into four strength categories: mild, moderate, potent and super potent. Different strengths are used by doctors depending upon the patient and the scale and severity of the condition.

The risk of side effects runs parallel with the strength of the steroid, the duration of therapy and, to some extent, how much the skin is exposed to the air. The face, genitals and skin fold areas will absorb more steroids than other areas. If you use a steroid under a bandage it will also have the same effect. Side effects on the skin may be apparent within two weeks' use. The potent and very potent steroids should be carefully monitored and limited to a few weeks' use, after which a milder steroid should be substituted if possible. Patients should be reviewed every three months. Only mildly and moderately potent steroids should be used in children to avoid potential growth retardation and long-lasting cosmetic disfiguration.

Vitamin D analogues



Vitamin D analogues calcipotriol, calcitriol and tacalcitol should not be confused with vitamin tablets or liquids that you may take as dietary supplements. Whilst their chemical structure may be based on a vitamin D3 molecule they have been modified to have a completely different effect.

They slow down the over-production of skin cells and stimulate differentiation of keratinocytes in the skin, correcting the abnormally fast cell turnover that characterises psoriasis. Unlike naturally occurring vitamin D, they have less effect on calcium metabolism, so the risks of high levels of calcium in the blood (hypercalcaemia) or in the urine (hypercalciuria) are reduced. Nevertheless there are limits to how much can be used at any one time to limit the possibility of these side effects happening.

The ease of use and low side effect levels have made these agents popular with medical professionals.

More recently one of these agents has been combined with a topical corticosteroid to help reduce skin inflammation as well.

For more detailed information, please visit our website or contact us. We can supply a comprehensive list of all treatments that are currently available or prescribed for the treatment of psoriasis and psoriatic arthritis.

We are not recommending these treatments, but are making the information available to allow you to understand the difference and scope of therapies used. If you have concerns about your current treatment, you are strongly advised to consult your doctor, dermatologist or healthcare provider.

Source:
This article is adapted from information contained on our website www.papaa.org

At the Royal Free Hospital in Hampstead London a psoriatic arthritis and psoriasis clinic is being developed by consultant rheumatologist Dr Arvind Kaul. Dr Kaul's vision is of a completely integrated psoriatic arthritis/psoriasis service. To this end, Dr. Kaul and his dermatology colleague, Dr. Sandy McBride now run a combined psoriatic arthritis / psoriasis clinic.

The service will develop further for the benefit of patients once a psoriatic arthritis clinical nurse specialist is recruited. The nurse specialist will act as a focal point of contact for patients as well as GPs and other practitioners. In addition, Dr Kaul is supervising clinical research and aims to commence laboratory research with the aim of clarifying the mechanisms which underlie psoriatic arthritis and psoriasis.

Dr Arvind Kaul

Dr. Kaul is happy to see patients with psoriatic arthritis from anywhere in the UK. Patients should first contact their GPs if they wish to be referred on the NHS. Dr. Kaul can also be contacted via his secretary on 020 7794 0500 extension 36538. He also works privately at London Bridge Hospital, where he can be contacted on 020 7234 2155.

About Dr Kaul

Dr. Arvind Kaul was appointed as a consultant in rheumatology and acute medicine in July 2007. He is responsible for the dedicated psoriatic arthritis clinic and is a member of GRAPPA, the Group for Research and Assessment of Psoriasis and Psoriatic Arthritis which fosters joint working between specialities for the benefit of patients.

About The Royal Free Hampstead NHS Trust

The hospital has around 900 beds and sees about 700,000 patients a year from all over the world. It employs around 4,600 people and has a turnover of about £450m.

Services include a major accident and emergency service, all branches of surgery and medicine, a renal service serving the whole of north London, paediatrics, maternity services, care of elderly people, an adolescent psychiatric service and one of two high security infectious diseases units in the country.

The hospital is renowned for its specialist services including liver, kidney and bone marrow transplantation, renal, AIDS/HIV, infectious diseases, plastic surgery, immunology, paediatric gastroenterology, ENT surgery and audiological medicine, amyloidosis and scleroderma.

It is also a leading cancer centre with a range of specialist diagnostic and treatment services in oncology and haematology and a major neuroscience base with a network extending throughout north London and into the Home Counties. There are associated internationally recognised research and training programmes.

The hospitals and associated medical school conduct medical research, much of which is of international status, and constitute a leading site for the training of doctors, nurses, midwives and professions allied to medicine.

Contact:

Royal Free Hospital
Pond Street, London, NW3 2QG
020 7794 0500
0844 8480700

www.royalfree.nhs.uk

Suffered for years – a case history

I was diagnosed with psoriatic arthritis in October 2009. For years I have had problems with swollen joints. I visited my doctor several times, explaining the joint that was swollen at that point. I went through several blood tests and x-rays but nothing was pinpointed and so the doctors did nothing.

I had been told that drinking cola could affect joints so I swore off this. I went away on holiday for a week in June 2008; I was still drinking other fizzy drinks but by the end of the holiday I could hardly walk. So I just thought it was all fizzy drinks and so decided to keep off these. This seemed to work so I thought nothing else of it.

In August 2008 I moved home and so had to change doctors. My joints at this point were fine, I had still some swollen toes but as they did not hurt I thought nothing of it.

Then in June 2009 I went away [*on holiday*], I don't know if heat has something to do with it but my ring finger became swollen and very painful, a few nights I ended up in tears. I rang and made an appointment with the doctor whilst I was still away. A few days after I got home I went to my appointment, I explained everything that had ever swollen and what my previous doctor had done.

My new doctor decided to start from the beginning so again it was blood tests and x-rays, these all again showed nothing. In the time I was going through all this my left knee also became swollen and painful. However this time the doctor decided to refer me to a rheumatologist, I waited six weeks for my appointment.

I went in [*and*] explained all the joints that had swollen, the rheumatologist asked if I had any other medical conditions, I told him I had psoriasis on my scalp; the minute I said that he told me he knew what I had. He gave me leaflets and explained the medication I was to start on.

I realised that the diagnosis made perfect sense, when I first went to the doctors at 18 years of age for a diagnosis on what the scales on my scalp were I also went for a swollen toe. I was told I had psoriasis on my scalp and that the toe was just an inflammation virus and that I was told to take ibuprofen. This I now realise was probably the first sign of psoriatic arthritis.

I have now been on sulfasalazine for five months. I have reacted well with the medication and feel so much better than I did before. I still have bad days with my joints, particularly with my knee, but these are becoming few and far between.

I know that this will never go away but [I] know how to deal with it. My future seems a lot brighter now I know what is wrong with me.

Thank you for submitting your case history – other case histories/experiences welcomed for publication.

Behind the Headlines

Your guide to the science that makes the news

Have you ever read a headline or half heard a news report about a new scientific breakthrough? Do you often wonder whether the story is correct or just another piece of irrelevant news?

NHS Choices, which is the online front door to the NHS and the country's biggest health website giving you all the information you need to make choices about your health, has a section on the site called *Behind the Headlines*, which is your guide to the science that makes the news.

The aim of the section is to shed light on news reports and explain their origins.

A typical approach to a news story will show:

- **Where the headline appeared**

This could be a daily news paper, magazine, TV or even online.

- **Where the story came from**

This might say the original researcher's name or where the research was carried out and how it was funded, such as, a grant or a commissioned piece of work on behalf of a single commercial company.

- **What kind of research it was**

This will explain if the research was new or just an analysis of other existing research.

- **What did the research involve?**

This will explain how the research was developed and how it was carried out.

- **What were the basic results?**

This will give the data and numbers of people involved, often described as the 'power' or 'powered'. The larger the research sample, potentially more reflective it will be of real life.

- **How did the researchers interpret the results?**

This may show how the researchers came to their conclusions. Some headlines often emphasise parts of a study, which weren't the main aim of the project, therefore making conclusions which were not the intention of the researchers.

- **Conclusion**

This will try to put the research into context and provide a review of whether the results are valid, significant and most of all robust.

It is important to look beyond the initial headlines and try to see who promoted the story, therefore is it a piece of editorial advertising or does the news have real merit and is indeed a scientific breakthrough.

For further information about:
NHS Choices Behind the headlines visit:
www.nhs.uk

Genital psoriasis

What is genital psoriasis?

As the term suggests, genital psoriasis is psoriasis in the genital area. Sometimes this can be the only area affected by psoriasis, and the problem can range from just a few small spots to large plaques.

Usually, genital psoriasis does not have the typical appearance of thick red scaly plaques that are seen in other areas. It appears as bright red, shiny patches of skin with no scale on top. The reason for this is that friction between the two skin surfaces in the groin rubs off the scales.

Genital psoriasis can also affect children, especially babies, and this is known as napkin psoriasis.

What causes genital psoriasis?

Psoriasis commonly affects genital areas, but it is not always easy to identify what the triggers are. In the flexures and groin area it may be worsened by tight clothing rubbing the skin, by deodorants or antiperspirants, or by contraceptives – sheaths, caps and spermicides, sanitary towels or tampons, harsh toilet paper, thrush or sexual intercourse.

Why does genital psoriasis sometimes require specific treatments?

The absence of scaliness is most obvious in the skin flexures or folds because the continual friction between the two skin surfaces rubs them off. The enclosed area of a skin fold and thinness of the skin in sensitive areas can affect the action of topically applied treatments (ie creams and ointments). In both there is a tendency for an increase in the absorption of the treatment through the skin, thereby enhancing its effect. In addition, the potential for a cream or ointment to cause irritation is increased when it is applied in a flexure and comes into contact with two skin surfaces that are rubbing together. For these reasons specific creams and ointments are advisable for use in sensitive areas of the skin; some creams or ointments are not recommended at all.

Coping with genital psoriasis

Skin diseases can be difficult to cope with and a skin disease that affects the genitals can be doubly so. It can be embarrassing to discuss genital psoriasis with a doctor or nurse.

Try to remember there is nothing to be embarrassed about. Overcoming your natural reluctance to discuss these matters, and learning how to be up-front with your doctor and loved ones can make coping with psoriasis much easier.

Honesty and openness are key factors in coming to terms with your situation. If your partner knows how genital psoriasis is affecting you, he or she will be better able to support you emotionally and physically. Equally, your doctor will be in a better position to help you.

Remember, they want to help you, so let them know how you are feeling.

Genital psoriasis can cause irritation and discomfort during sexual intercourse which can affect sexual relations with your partner. Effective medication will help to relieve this problem. In addition, it may be helpful for the man to wear a condom as this might limit any irritation or discomfort. It is also important to wash all medications from the genital area prior to intercourse to avoid transfer of the medications to your partner.

Men may find it difficult to have an erection because their penile skin may contain cracks or bleed. This can lead to tensions within a sexual relationship therefore talking to your partner or being in an understanding relationship can help defuse any emotional complications.

Using a condom during intercourse may reduce any discomfort, as the condom will act as a barrier to avoid skin-to-skin and fluid to skin contact, which cuts down on irritation. Good personal hygiene prior to intercourse is equally important to avoid any transference of medications to your partner. After intercourse, cleansing the area and reapplying the medications or emollients as directed by your doctor will also aid recovery.

During a flare should I refrain from sexual intercourse?

Not necessarily, but a flare may be exacerbated by sex, due to friction causing a Koebner reaction and it may be painful.

What should I do if I have genital psoriasis?

Genital psoriasis may also affect the surrounding area in the groin. It rarely appears in the vagina. If you develop psoriasis of the genitalia you should always consult your doctor. Do not be embarrassed.

Genital psoriasis can sometimes look similar to a fungal or bacterial infection, even contact dermatitis, so your doctor may need to check the diagnosis with a laboratory test before starting any treatment. The delicate skin in the genital area may mean you need a weaker psoriasis treatment than elsewhere on your body. You should bear in mind that you may be susceptible to irritant and allergic reactions from your under garments by harsh laundry detergents and current medications.

It is important to remember that psoriasis is not due to an infection and is not catching. Consequently, when you are in a loving relationship with a partner who knows about your psoriasis, it should not interfere with your sex life. If you are with a new partner, explain your condition before you become intimate.

If your partner is worried, you can show him or her leaflets on psoriasis, ask your doctor to explain the problem, or even attend a genito-urinary clinic together for a joint check-up. Treatment at genito-urinary medicine (GUM) clinics is free and confidential. You can find their telephone number and clinic times by phoning your local hospital.

Affected sites

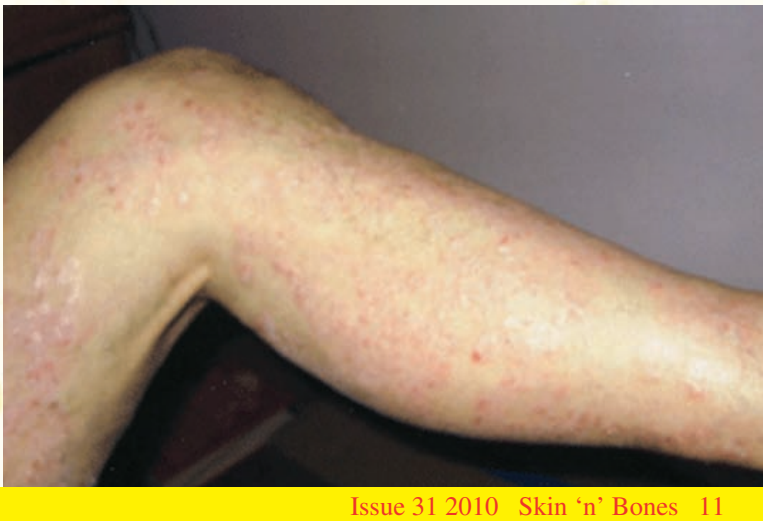
- **The pubic region** – a common site of genital psoriasis which can be treated in the same way as scalp psoriasis but be aware that the skin in this area is likely to be more sensitive than on the scalp.

- **Upper thighs** – the appearance of psoriasis on the upper thighs is likely to be small round patches which are red and scaly. Any psoriasis between the thighs can become more easily irritated by the friction caused of thighs rubbing together when mobile. Reducing the friction between your legs will relieve sweatiness and irritation.

- **Skin folds between thigh and groin** – psoriasis in this area will normally appear non-scaly and reddish white in the creases between the thigh and groin and may become sore with cracks forming. Overweight or sporting people may be susceptible to thrush in the skin folds which can be mistaken for psoriasis. Like genital psoriasis it can cause the same irritation from friction of the skin so a correct diagnosis is essential for proper treatment.

- **Psoriasis of the vulva** commonly appears to be smooth, non-scaly and red. In this sensitive region irritation can be caused by scratching and may become infected and worsen the psoriasis. Scratching can also produce dryness, thickening and further itching of the psoriasis. Always make sure you wash your hands and finger nails. Personal hygiene is essential and paramount.

- **Genital psoriasis in women** will normally affect the outer skin of the genitals. The vagina and mucus membranes surrounding it will not normally be affected. The urethra (the canal expelling urine) is not normally affected.



Genitial psoriasis

- In men the appearance of psoriasis on the penis may consist of small red patches on the glans (tip of the penis) or shaft, and the skin may also appear to be shiny. Psoriasis of the penis can affect either those who have been circumcised or not.

- **The anus** – psoriasis on the anus and surrounding areas will normally appear to be red, non-scaly and can become itchy and weepy and sore. Again psoriasis in this area may be confused with other infections such as yeast fungal infections, worms, haemorrhoid itching and streptococcal infections. It is essential that you consult your doctor for a prompt and correct diagnosis. In some cases symptoms can include bleeding, pain during bowel movements, dryness and itching, together with soreness.

- **Buttocks** – psoriasis in the buttock folds may appear as red non-scaly or red with very heavy scaling. The skin in this area is not as fragile as that of the groin.

What treatments may or may not be used in genital psoriasis?

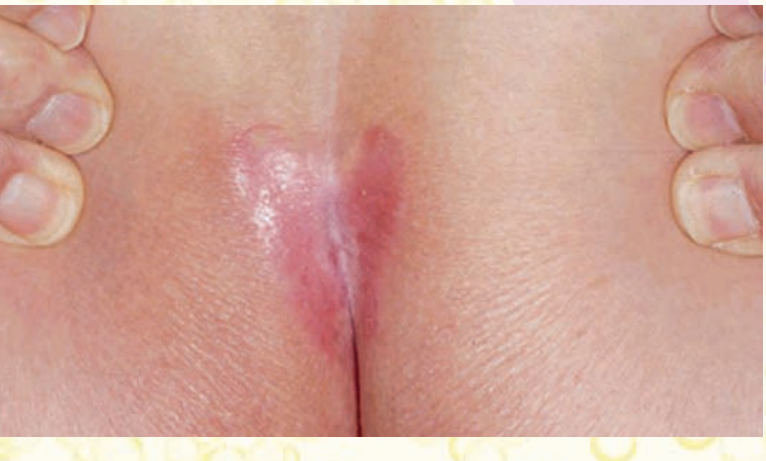
Prescribed treatments for genital psoriasis usually have good outcomes but you must always be careful to comply correctly with your doctor's directions as these skin areas are delicate.

When treating genital psoriasis it is important to keep the affected areas moisturised. When using moisturisers if any irritation occurs this may be due to sensitivity to some of the ingredients in them.

If you develop genital psoriasis, you should discuss it with your doctor, who will be able to advise you on suitable treatments. Here is a summary of topical treatments which may or may not be used in genital psoriasis.

Emollients are an important part of the daily care of psoriasis in all parts of the body, including the genitalia. They help to make the skin more comfortable. In addition, there is a range of topical treatments available - creams and ointments - that your doctor can prescribe.

Topical vitamin D creams and ointments are effective in treating psoriasis and the newer types are less likely to cause irritation. However, some of them do have the potential to irritate sensitive areas such as the genitalia. Some doctors recommend cautious use of vitamin D analogue creams and ointments on genital skin.



Topical steroid creams may be recommended for sensitive areas. However, care should be taken with their use as the potential for increased absorption may lead to side effects such as skin thinning. For this reason low strength topical steroids are favoured for use in the genital area. It is also important that topical steroids are not used for long periods of time or without close supervision from your doctor. Prolonged use of high potency steroids can also cause stretch marks and you may become resistant to these medications in clearing the symptoms successfully.

Treatment should never be stopped abruptly as this may trigger a rebound flare of your psoriasis.

Topical steroids may also be combined with antifungal and antibacterial agents because infections with yeasts and bacteria in warm moist skin creases such as the groin are more common.

Dithranol and Vitamin A derivatives (retinoids) are not usually recommended for use in skin flexures because of their tendency to cause irritation.

Coal tar preparations are not usually recommended in genital areas because they can cause irritation, especially to the areas such as the penis, the scrotum, the vulva or other cracked skin.

Calcineurin inhibitors (tacrolimus and pimecrolimus) are effective in treating genital psoriasis and don't have the side effect of thinning the skin that limits the use of topical steroids. They do however often cause an uncomfortable burning sensation when applied and can reactivate sexual transmitted infections such as herpes and viral warts.

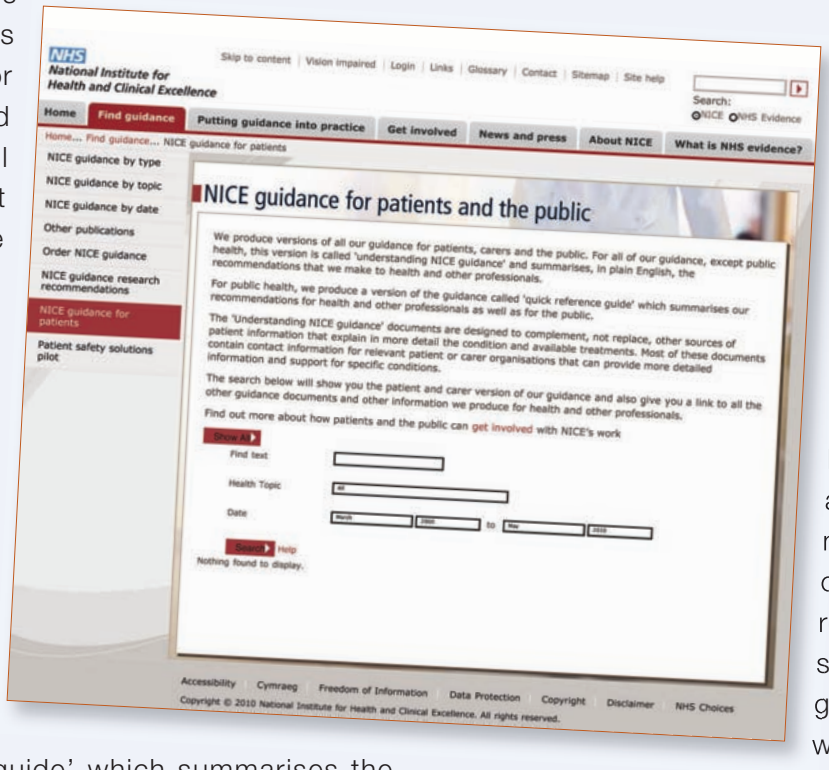
UV light treatment is not usually recommended for genital psoriasis due to an increased risk of skin cancer in this area. Men with psoriasis undergoing UV light treatment are specifically advised to cover the genital area during treatment to reduce the risk of cancer in this area.

Remember: It is also advisable to get any rash that appears on the genitals checked, as there are other conditions that can also affect these areas. Never assume that because you have psoriasis that all rashes that appear will be due to psoriasis.

NICE guidance for patients

NICE has launched a new page on the website that will allow, for the first time, patients, carers and members of the public to search for the versions of guidance that are written for them.

NICE produces different versions of all its guidance for patients, carers and the public. For all guidance, except public health, the version is called 'understanding NICE guidance' and summarises, in plain English, the recommendations that are made to health and other professionals.



For public health, NICE produces a version of the guidance called a 'quick reference guide' which summarises the recommendations for health and other professionals as well as for the public.

But until now, patients and the public have had to look through the individual pieces of NICE guidance in order to identify the relevant patient versions.

"The new webpage will allow users to find all of the understanding NICE guidance and quick reference guides in one place. This is something that members of the public have said they would find extremely useful," said Victoria Thomas, associate director of the patient and public involvement programme at NICE.

"The new page will allow NICE to provide patients and the public with easy access to information that is specifically tailored to meet their needs. This in turn can help people make informed decisions about their health and wellbeing, and the treatment options available to them".

NICE is a corporate member of the Plain English Campaign, which highlights that the guidance is written in plain English and in the clearest possible way.

In addition, NICE is part of the Information Standard, a nationally recognised standard for health and social care information producers. This confirms that the patient versions of our guidance are reliable and trustworthy, and are appropriate for their intended audience.

Lay versions of NICE guidance have also picked up a number of awards over the years. Most recently, two understanding NICE guidance documents were recognised at the 2009 British Medical Association (BMA) patient information awards.

The document for the clinical guideline on stroke (CG68) was commended, and the leaflet on the interventional procedure 'Stent insertion for bleeding oesophageal varices'(IPG265) was highly commended.

The judges commented that the interventional procedure leaflet was well written and that the list of suggested questions for patients to ask their doctors was very useful. They praised the leaflet as being 'a clear and concise treatment of the subject'.

The new webpage can be found at: http://www.nice.org.uk/patientsandpublic, and has been given a permanent web link so that patients can bookmark it as their homepage for NICE guidance.

physicool™
Consistent cooling when you need it

Physicool is a new and unique, stretchy, reusable bandage that combines cooling, compression and support. Physicool provides instant treatment for inflammation and bruising of muscles, tendons and ligaments.

The manufacturer says it is highly effective and quickly reduces swelling and pain. The bandage can be applied in seconds, you just need to have it at hand, and its effects are long lasting, even after the bandage is removed.

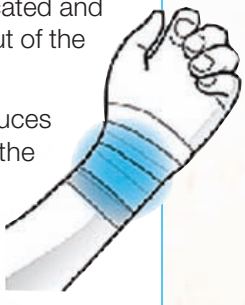
Physicool works by drawing heat out through rapid evaporation, as opposed to most other products that work by driving cold in.

It can be used for domestic, sport and leisure use.

Why Physicool?

- Quickly reduces swelling and pain
- Helps speed up the healing process
- Easy to apply, even one-handed
- No need for refrigeration
- Reusable cooling bandage

The Physicool bandage is a specially fabricated and treated bandage that can be used straight out of the packet.



The Physicool rapid cooling bandage reduces recovery time from new injuries drastically, the immediate compression keeps your initial injury swelling down, while the instant cooling relieves your pain and speeds your healing process.

Its effects are immediate and long lasting and can be used to reduce pain both on new traumas or existing conditions. Sprays cost £16.99 for a 500ml bottle and a small bandage (10cm x 2m) is £9.99.

The product was featured on the BBC television programme Dragons' Den last year and was supported by entrepreneur Deborah Meaden.

For further information: **Tel: 07778 274 265**
Email: info@physicool.co.uk
Web: www. physicool.co.uk
The products are available from chemists and other retailers.

Arthritis Research UK

Arthritis Research UK

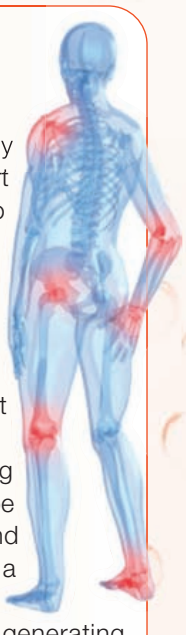
The UK's biggest arthritis research charity has changed its name as one of many positive changes in taking on a more proactive role and relaunching the fight against arthritis.

The Arthritis Research Campaign (ARC), the fourth biggest medical research charity in the UK, became Arthritis Research UK last March.

The charity is making many changes to increase both the profile of arthritis, which affects around ten million people, and also the internal workings of the organisation itself.

As well as continuing to fund research, Arthritis Research UK will take on a greater leadership role on behalf of people with arthritis; campaign on matters of importance; and play a more active lobbying role in order that the condition is taken more seriously not only by government but by the medical profession and the wider public.

Chief executive of Arthritis Research Dr Liam O' Toole said: "We are making a number of changes and a new name is one of them. We are relaunching the fight against arthritis and we will be building on our leadership role in research which we expect to have a more direct impact on the lives of sufferers. To further support this we will be rapidly building up our fundraising activities. We have also developed ten ambitious goals, which we aim to deliver by 2020.



"As an organisation we have been relatively passive in speaking out and so we plan to start campaigning on matters of importance to patients. We will be a much more dynamic charity, more proactive and vocal. We owe it to the people we represent to make sure we maximise the impact of everything we do."

The charity has also relaunched its website and is improving and redesigning its patient information material.

Dr O'Toole added: "Arthritis is a growing problem and many people feel that nothing can be done. It's time to change that perception and reach out to more people. We have a responsibility to help individuals realise that something can be done. And as a result of generating greater awareness and greater clarity of purpose we will be able to raise more money for our core remit - research."

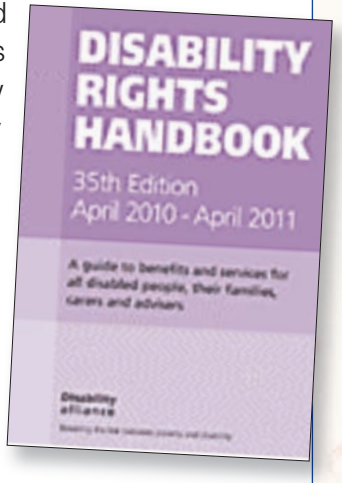
Arthritis Research UK
Copeman House, St Mary's Gate
Chesterfield, Derbyshire, S41 7TD United Kingdom
Tel: 01246 558033 Fax: 01246 558007
Email: enquiries@arthritisresearchuk.org
www.arthritisresearchuk.org

Disability Rights Handbook

(35th edition)

April 2010 - April 2011

If you want to know which benefits you can claim and don't know your rights, the Disability Rights Handbook is the guide for you.



Written in an easy to read style the Handbook contains everything you need to know about social security benefits, tax credits and related services for disabled people.

Fully updated each year, this essential reference book has helped hundreds of thousands of disabled people, their families and carers as well as professional advisers.

The handbook has been completely restructured to reflect changes across the whole benefit system following the introduction of employment and support allowance.

Publisher: Disability Alliance Educational and Research Association
ISBN: 978-1-903335-50-5
Also available on CDROM
Price £27.50 per copy (*£12.00 for people on benefit*)

About Disability Alliance:

Disability Alliance is a national registered charity working to improve the living standards of disabled people, breaking the link between poverty and disability.

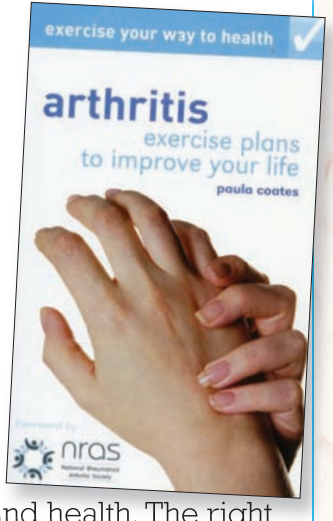
It provides information on social security benefits, tax credits and social care to disabled people, their families, carers and professional advisers.

For further information visit:
www.disabilityalliance.org

New book:

Arthritis: Exercise plans to improve your life

By: Paula Coates



Approximately 10 million adults consult their GP each year with arthritis and related conditions. Exercise your way to health: *Arthritis illustrates* how to include a simple fitness programme in your life, while considering the specific challenges raised by arthritis. This simple guide gives you an understanding of your diagnosis and how it impacts on your body and health. The right lifestyle choices and exercise can reduce arthritic pain.

Arthritis should not stop you living a full and active life. You should see improvements within 6 weeks, when you can re-test your fitness level. This is a motivational book for a new lifestyle and a happier and healthier you!

About the author

Paula Coates is a chartered physiotherapist, back pain specialist and author of *Running Repairs*, journalist, and is a clinical lecturer for the MSc in neuromusculoskeletal physiotherapy at Kings College London.

ISBN: 978 1 408 10702 7
Publisher: A & C Black Paperback 2010
Price: £6.99 RRP
(£4.42 from Amazon* online)

Letters

Q Dear PAPAA,

Thank you for sending me your free information pack about psoriasis and psoriatic arthritis which I have found very useful. I notice on your publications list that there are one or two titles that I am interested in but I am not sure how to go about sending the payment. I am reluctant to send cash through the post so can I give you my card number for you to take the payment that way?

Look forward to hearing from you.

RH

A Dear RH,

I am pleased to say that we now have the facility on our website to take payment by credit/debit card for purchases, subscriptions and renewals. (see page 20)

If you do not have access to the internet we can take the payment over the phone or you can still pay by cheque in the normal way.

PAPAA

Q Dear PAPAA,

I am a 44 year old lady and have had psoriasis for 36 years and psoriatic arthritis for 13 years.

Whilst at a craft fair in the summer I bought and tried a new shampoo that stated it helped psoriasis. I am delighted to say that it is the only shampoo that I've used (and I've tried a good few!) that stops the terrible itching. It is goats milk and camomile shampoo and I've now ordered some more.

Thanks for a great magazine.

LC

A Dear LC,

We are pleased to hear you have found a shampoo that is working well for you. If any other readers would like to pass on tips as to what has worked for them we would love to hear from you.

PAPAA

Q Dear PAPAA,

I read in a magazine that eating oily fish will benefit my psoriasis.

JK

A Dear JK,

A healthy diet is important for wellbeing and can reduce your risk of many long-term illnesses including inflammatory conditions such as psoriasis. However there is no link between what you eat and the severity of psoriasis.

The British Nutrition Foundation suggests eating at least 300g of oily fish per week for general health (such as mackerel, herring, salmon, trout, sardines, or pilchards) Although in some studies fish oil (salmon) has been shown to benefit psoriasis.

PAPAA

Q Dear PAPAA,

I have psoriasis and I have noticed that just lately my fingers are swollen. I have heard that you can have a type of arthritis with psoriasis. Do you think I may have it?

TP

A Dear TP,

Depending on where the swelling appears you may have a type of arthritis which is linked to psoriasis. If it affects just the last joint of your fingers, with some possible nail changes and is not the same in both hands then it is possible that you have the most common form of arthritis that is association with psoriasis. This is not likely to get much worse and should not affect any of your other joints.

If other joints are affected you may have a more progressive form of the disease and it is recommended that you see your GP as soon as possible.

PAPAA

Please note: letters and emails have been edited and names withheld for privacy

Psoriasis questions

Q: *Can I use deodorants if I have psoriasis in my armpits?*

A: Deodorants can sometimes aggravate psoriasis in the armpits or trigger a flare-up. This is because of the chemicals in them that can irritate the skin.

There are deodorants designed for sensitive skin (sometimes referred to as hypoallergenic) and they contain less of the chemicals that can cause irritation and they may also contain emollients to help moisturise your skin.

Q: *Can I go swimming pool?*

A: Psoriasis is not contagious so there is no reason why you should not swim because of psoriasis. The chlorine in a swimming pool may dry out your skin, so it is a good idea to shower as soon as possible to remove the chlorine and then apply a good moisturiser.

Q: *Will vitamins help/aggravate my psoriasis?*

A: *There is no medical evidence that taking vitamins will either help or aggravate your psoriasis. If you have adequate vitamin nutrition in your diet taking supplementary vitamins should not be necessary.*

Q: *Will the sun help my psoriasis?*

A: Those who have psoriasis find that the sun helps to improve their skin's appearance. For some the change is dramatic, with red scaly patches almost disappearing altogether during summer months in a warm climate.

Because ultraviolet light is so effective for so many with psoriasis, it is often used in various artificial forms by doctors. Ultraviolet treatment with a sun lamp is often given in hospitals for plaque psoriasis (the most common type) and guttate psoriasis. In severe cases of psoriasis, dermatologists may use a treatment known as PUVA – P for psoralens plus UVA. Psoralens are chemicals found in certain plants which make the skin respond to UVA, the least dangerous form of UV light.

Psoriatic arthritis questions

Q: *What does the word chronic mean?*

A: A persistent and lasting disease or medical condition or one that has developed slowly. Not to be confused with acute, which is a disease with a rapid onset and/or a short course.

Q: *What is the connection between nail psoriasis and psoriatic arthritis?*

A: Psoriasis can affect both fingernails and toenails. The percentage of those with psoriasis who have nail involvement is thought to be 50%. In psoriatic arthritis this may rise to 80%.

For some unknown reason the fingernails are more often involved than toenails.

Q: *Can psoriatic arthritis affect the eyes?*

A: Yes, it's called uveitis which means inflammation of the uvea. This can affect the iris (iritis), ciliary body (cyclitis) or the choroid (choroiditis). Symptoms depend on whether all or just part of the uvea is affected, but may include:

dull, aching pain in the eye; redness; blurred or misty vision; a muddy appearance to the coloured iris in the affected eye; or a pupil that may be smaller than on the other side and irregular in outline.

Risk is higher if you have B27 tissue type which is common in spondylitis sub-groups; it can occur whether arthritis is currently active or not.

Note: children with psoriatic arthritis should have regular screening tests for uveitis as they may not develop symptoms until their eyesight has been damaged and irreversible visual impairment.

Q: *What does the word arthropathy mean?*

A: Arthropathy (ar throp ath e) - any disease affecting a joint, such as arthritis.

Scientists put psoriasis drugs to the test

Clinical trials to test the effectiveness of two prescription drugs for the debilitating skin condition psoriasis have revealed significant differences that should help inform physicians treating patients with the condition.

Researchers at The University of Manchester compared the drugs etanercept and ustekinumab, relatively new biological therapies that have proved effective in the management of moderate to severe psoriasis.

Little research has been done to test the benefit-risk profiles of these new biological agents or compare their relative effectiveness. The Manchester-led international study tested the two drugs on 903 patients with moderate to severe psoriasis over a 12-week period.

The team, headed by world-renowned dermatologist and psoriasis expert Professor Chris Griffiths, found that there was at least a 75% improvement in the severity of psoriasis symptoms in 56.8% of patients who received twice-weekly 50mg sub-cutaneous injections of etanercept after 12 weeks.

Ustekinumab was given to patients in two doses – 45mg and 90mg – and involved just two sub-cutaneous injections over the 12-week period. A 75% improvement in symptoms was observed in 67.5% of patients taking the 45mg dose and 73.8% receiving the 90mg dose.

"Our findings show that the efficacy of ustekinumab at either dosage was superior to that of high-dose etanercept using the 75% improvement measure over a 12-week period," said Professor Griffiths, who is based at Salford Royal Hospital, Greater Manchester.

"Similarly, a higher proportion of patients using ustekinumab were reported to have no or minimal disease symptoms after 12 weeks than those given etanercept – 70.6% at 90mg ustekinumab compared to 49.0% receiving etanercept."

About one in 50 people are afflicted by psoriasis. The condition is currently incurable and causes significant impairment in a sufferer's quality of life. In severe cases more than 20% of the skin's surface area can be affected. Therapeutic agents used for the management of the condition commonly target the underlying inflammation.

Immunosupressive agents, such as methotrexate and ciclosporin, have proved effective in treating psoriasis but new biological agents that block selective stages of the body's inflammatory process now provide alternative therapies.

Etanercept and ustekinumab are two such agents.

The research, published in the New England Journal of Medicine (14 January 2010), also charted the number and type of adverse reactions for both drugs.

Professor Griffiths said: "The safety of ustekinumab and etanercept, including the rates and types of adverse events and laboratory abnormalities, appeared to be generally similar with short-term treatment.

"There were, however, more injection-site reactions with etanercept but this may be accounted for by the fact patients received more injections of this drug than ustekinumab."

He added: "The results of this study could have implications for determining the optimal approach to the treatment of psoriasis and, in particular, the need for therapeutic strategies targeting the body's immune system to provide the greatest benefit and safety."

Source: Press Release
Faculty of Medical and Human Sciences
The University of Manchester, 14 January 2010

Reference:
Comparison of Ustekinumab and Etanercept for Moderate-to-Severe Psoriasis
Christopher E.M. Griffiths, M.D., Bruce E. Strober, M.D., Ph.D., Peter van de Kerkhof, M.D., Vincent Ho, M.D., Roseanne Fidelus-Gort, Ph.D., Newman Yeilding, M.D., Cynthia Guzzo, M.D., Yichuan Xia, Ph.D., Bei Zhou, Ph.D., Shu Li, M.S., Lisa T. Dooley, Dr.P.H., Neil H. Goldstein, M.D., Alan Menter, M.D., for the ACCEPT Study Group
New England Journal of Medicine Volume 362:118-128
January 14, 2010 Number 2

SMC accepts ustekinumab

Scottish Medicines Consortium (SMC) accepted ustekinumab for use within NHSScotland for the treatment of moderate to severe plaque psoriasis in adults who have failed to respond to, or who have a contraindication to, or are intolerant to other systemic therapies including ciclosporin, methotrexate and psoralen and UVA treatment (PUVA).

Ustekinumab is a new treatment that slows down the inflammation. It is given as an injection at weeks 0 and 4 and then every 12 weeks afterwards. Treatment should be discontinued if patients have not shown any response after 28 weeks.

- In a study of patients treated with ustekinumab compared with an alternative treatment, significantly more patients achieved at least 75% improvement in their psoriasis.
- A condition known as injection site erythema was less frequent in those treated with ustekinumab. Rates of infections or serious infection were similar between both treatment groups.
- This SMC advice on ustekinumab takes account of the benefits of a patient access scheme (PAS). A PAS is a scheme proposed by a manufacturer in order to improve the cost-effectiveness of a drug and enable patients to receive access to cost-effective new medicines.
- SMC accepted ustekinumab for use because, when the benefits of the PAS were included in the economic case, the manufacturer's justification of the treatment's health benefits in relation to its cost was favourable enough to gain acceptance. This SMC advice is dependent upon the continuing availability of the PAS in NHSScotland.

Ustekinumab, brand name Stelera®, is a prescription only medication (POM).

About Scottish Medicines Consortium (SMC)

The remit of the SMC is to provide advice to NHS Boards and their Area Drug and Therapeutics Committees (ADTCs) across Scotland about the status of all newly licensed medicines, all new formulations of existing medicines and new indications for established products (licensed from January 2002). This advice will be made available as soon as practical after the launch of the product involved.

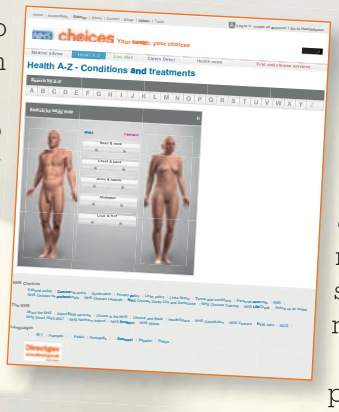
Source:
SMC briefing note; Number 27 February 2010.
www.scottishmedicines org

What is an information prescription?

Information prescriptions were originally a commitment in the Department of Health white paper 'Our health, our care, our say' published in January 2006.

The paper made a commitment to improving access to appropriate information for people with health or social care needs.

Information prescriptions are offered to everyone with a long-term condition or social care need, in consultation with a health or social care professional. Information prescriptions guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.



Information prescriptions are nationally recognised as a source of key information on services and care that is seamlessly and formally integrated into the care process.

Getting an information prescription

An information prescription tells you about:

- Your condition.
- Your treatment options.
- Care services (from equipment to help you get around the house to specialised exercise classes).
- Benefits you may be able to claim.
- Housing support.
- Self-help and support groups.

It will tell you where to find out more, with contact details and website addresses that you might find useful. It tells you about local services and groups that could help, as well as national ones.

You can discuss your information prescription needs with your GP or other healthcare professional or with your social care worker, usually as part of your care plan.

On NHS Choices you can create your own information prescription for a number of long-term conditions by using the Health A-Z.

www.nhs.uk/Conditions/Pages/bodymap.aspx

Market Place

Here are a few items that have been brought to our attention by our readers.These are for your interest and in no way are we endorsing or recommending these products.

We've been sent some interesting items for this edition, so thank you if you have provided suggestions.

Have you ever had a problem applying creams to your back? Well a solution might be a product from **Viva Direct**, a long-handled lotion applicator, which lets you apply products to your back and other inaccessible parts of the body without having to tie yourself up in knots.

Fill the applicator head with your lotion, and then let the 19 rolling balls soothe and invigorate your skin as they evenly massage it in.

Product Code 154 1584 Price: £9.95

If you are having trouble with your hand or fingers here is a product which might help, available from **Healthy Living Direct.**

The Table Top Nail Clipper has been specially designed to assist those with limited dexterity to cut fingernails.

Product Code 16052 Price: £9.99

Blister packs of pills are a common source of problems. They can be so fiddly. Pill Popper might provide an answer, also available from **Healthy Living Direct.**

Product Code 19727 Price: £4.99

Getting the best prices online:

Price comparison sites - enter a search phrase 'compare prices' into a search engine and then access the sites directly.

Remember to check availability of products, cost of delivery and most of all whether the site is secured for eCommerce transactions.

- **www.dealtime.co.uk**
- **www.comparestoreprices.co.uk**
- **www.kelkoo.co.uk**
- **www.google.co.uk/products**

Secure sites will have a certificate on the site, such as **GoDaddy, DigiCert, VeriSign, Thawte** and **Comodo**. These certificates will allow you to check the validity, if you are suspicious.

Contact details for the above products:

Viva Direct
0844 482 2803 www.vivadirect.co.uk

Healthy Living Direct
0871 472 4250 www.healthylivingdirect.com

A & C Black (Publishers) Ltd
020 7758 0284 www.acblack.com

***Amazon**
(Online only) www.amazon.co.uk

If you come across products or items that you have found useful or you think others will find of interest please let us know. There may be similar products on the market made by other manufacturers that are as useful so keep your eyes open

Psoriasis Shop

www.psoriasis-shop.org or www.papaa.org

New eCommerce website set up for people affected by psoriasis and psoriatic arthritis.

Following the demand from members and website users, you may like to know that we have set up an online psoriasis shop.

This site is secure and payments are accepted using credit or debit cards, which include Visa and MasterCard.

You can:

- Order free information
- Join and pay for your subscription
- Renew your subscription
- Make a donation
- Purchase from a selection of books
- Training programmes (tba).

The site is an extension of our existing site. Over time we will develop the service so users will be able to maintain their own details and receive dedicated relevant emails. The development and material available will be dependent on what users require and will change accordingly.

The site is linked from our main website www.papaa.org or can be accessed directly via www.psoriasis-shop.org